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ABSTRACT

This report describes visits of two Americans to Bratislava, (Slovakia) and Prague (Czech Republic) as part of a larger project providing technical assistance to improve the care and services for children with special needs in these countries. A summary of the Bratislava visit lists people met and places visited (with a brief description of each facility). Further discussion focuses on the role of family and consumer groups, health care for children with special needs, inclusion in school and community settings, policy, planning, and training. A similar summary begins the report on the Prague visit. The narrative focuses on family/consumer groups, community living for people with disabilities, health care for children with special needs, inclusionary education, partnerships between professionals and families, and philosophical issues. A final section addresses implications for the United States. The strength of the extended family as a support system and the universal availability of health care in Slovakia and the Czech Republic are noted. Recommendations for further technical assistance include: (1) model the parent/professional (or consumer/professional) partnership; (2) utilize the expertise and experience of Czech and Slovak families and professionals; (3) build strategic planning skills; and (4) coordinate visits of consultants. (DB)

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Parent Advocacy and Family-Centered Care for Children with Disabilities and their Families—Linking North American Experiences with European Initiatives

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Introduction

During 1991 and 1992 the nations of Czechoslovakia and Hungary initiated policies aimed at returning the care and services for children with special needs to their families and to communities. The governments of these countries sought technical assistance in this effort from the United States. A project was conceptualized which involved the identification of community sites in each country in which to assist the development of model programs and systems change. Project planners visited these communities in late 1991 and early 1992 to assess needs and convene a community action group in each site. Meanwhile, a core faculty of twelve professionals and parent advocates with national recognition was assembled in the United States to plan the curriculum for a congress to which the community groups would be invited in June 1992. Following national elections in the early summer of 1992, Czechoslovakia was divided into two independent republics, Slovakia and the Czech Republic, but representatives from each new republic continued to work together on the common aims of the project. A curriculum was built around areas of interest identified by the community groups from Slovakia, the Czech Republic, and Hungary (e.g. family support systems, outreach and regionalized health care services, early intervention services, inclusion in regular classrooms, etc.). The format of the June 1992 International Congress on Serving Children with Special Needs in the Community combined individual and panel presentations with faculty-led meetings of community groups to identify specific, achievable objectives. Federal representatives of each nation were also present and agreed to support the plans developed by the community groups. The community groups identified highly specific projects such as the development of a parent advocacy organization and parent-to-parent network in one community or the establishment of a family-centered early intervention program in another. In September 1992, project coordinators returned to all of the sites in each country to follow-up on the pursuit of objectives defined at the June Congress. All of the sites concluded that they wanted help developing systems of community-based, family-centered services and of family support and advocacy.

The visits to Prague and Bratislava were a follow-ups to the International Congress on Serving Children with Special Health Care Needs in the Community. Carl Cooley, MD. was assigned to the team from Bratislava, Slovakia. Polly Arango was assigned to the Prague 2 team. We spent the first part of our May, 1993, visit to Central Europe in Bratislava, and then traveled to Prague. The purpose of the visit was to experience firsthand the environment within which the teams live and work; the challenges to providing health care and education to youngsters with special health care needs in each of the republics; the progress that the teams had made on the plans they had developed at Georgetown; and what forms of technical assistance are appropriate now.

Summary of Bratislava/Podunajske Visit by Polly Arango and Carl Cooley May 8 - 12, 1993

People Whom We Met: * = original Bratislava team

- *Klara (Kaja) Frecerova, MD. (pediatrician, team leader)
- *Margareta Sulcova, M.D. (former Vice Minister for Public Health)
- *Margita Gazdikova (parent, secondary school supervisor)
- *Katarina Sabova, Ph.D. (psychologist, former Director of Department of Social Care in the Ministry of Labor and Social Affairs; returning to job at the Professor Matulay Institute)
- *Ladislav Cingel, ING (mayor, Dunajska Luzna)
- *Beata Fuknova, M.D. (pediatrician, Director, Infant Center)
- *Maria Kuhajdova (physical therapist, nurse at Infant Center)
- *Irena Szabova, M.D. (senior consulting neurologist, Infant Center)
- Antonio Chrebetova Ph.D. (psychologist, Infant Center)
- Anna Hrezova (social worker, former nun, Infant Center)
- Katarina Kadlicova, M.D. (pediatrician, Infant Center)
- Eva Rajecova, M.D. (internist, assistant to director of Institute of Tb/Resp Diseases = parent institution for Infant Center)
- Peter Kristufek, M.D. (Medical Director, Institute of Tb/Resp Diseases)
- Pavol Kailing (Director, Professor Matulay's Institute, site of integrated nursery school)
- Gail Klavana (American friend of Dr. Frecerova's; wife of Leighton Klavana who works with USAID-funded US-Slovak private enterprise development project)
- Eva Hacker (American friend of Dr. Frecerova; wife of US Chargé D'Affaires in Slovakia; leaving summer/fall 93 to be replaced by first Ambassador)
- Zlatica Janoutová, M.D. (pediatrician, Bratislava Children's Center)
- Vladimir Dockal, Ph.D. (psychologist, Director, Bratislava Children's Center)
- Karol Matulay, M.D. (neurologist, professor; respected emiratus (87 years old) scholar; director of Center of Early Diagnostics and Therapy, multidisciplinary evaluation clinic and early intervention center in Bratislava)
- Marta Carnogurska (founder of Pomoc pre Vas (Help for You) children's health foundation; wife of former prime minister of Slovakia prior to the split-up of Czechoslovakia; also works with and is a supporter of Dr. Matulay; mother of a child with a chronic illness)
- International Women's Club (Dr. Frecerova is a member; has encouraged group of influential women to support Infant Center's activities, e.g. raised money to purchased stroller for family of child with CP)
- Chance for Every Child Foundation (founded by Dr. Frecerova to support activities of the Infant Center)

Places Visited in Bratislava area (5/8/93 - 5/12/93)

Village of Dunajska Luzna

location of Infant Center described below

The village primarily through its mayor, Ladislav Cingel, supports the activity of the Infant Center and provides a possible site for more community-based activity, e.g. the development of a local parents group or parent-to-parent activity. The Chance for Every Child Foundation founded by Dr. Frecerova is based in this village with a mission of raising funds and public interest in the Infant Center and the children it serves.

Institute for Tuberculosis and Respiratory Diseases

Holy Cross Hospital
825 56 Bratislava
Podunajske Biskupice

This is a tertiary care medical center in Bratislava which is the parent institution supporting the Infant Center. It is no longer purely a tuberculosis hospital, but covers all areas of care. Dr. Frecerova works as a pediatric pulmonologist in the ambulatory clinic of this hospital. The medical director has been very supportive of Dr. Frecerova and of the Infant Center. This could be a basis for tertiary medical center outreach to other locations.

Specialized Infant Center

outreach project of Institute for Tb and Respiratory Diseases
Dunajska Luzna (village near Bratislava)

Originally a place for infants while mothers were treated for Tb, this in-patient and out-patient setting provides care for children with special needs and for children at risk who are hospitalized for "social reasons" (abuse, neglect, abandonment). There are a total of 50 beds of which about half are for children with disabilities. There are also out-patient services for children with special needs. The predominant intervention service is physical therapy employing the Vojta Method. There is also a pediatrician, consulting neurologist, psychologist, and social worker in addition to nursing staff.

Professor Matulay's Institute

Lipskeho 13
841 01 Bratislava

Named for a well-known neurologist*, this is a day habilitation and evaluation/diagnostic center for people with disabilities of all ages—adult programs include ceramics, arts, and sheltered workshop-type activity. There is also a segregated special school. The institute, under Pavol Kailing's leadership and with ideas from Dr. Sabova, has started an integrated preschool program that includes 3 or 4 children with disabilities (several with Down syndrome) and about 10 typical children. Because of a reputation for quality (staff and programming), parents of typical children seek places for their children in this preschool. The leadership of the Institute would like to extend the inclusion model to older children.

*see below, Center for Early Diagnostics and Therapy

Bratislava Children's Center

(Detske Centrum Bratislava)
Cyprichova 42
831 05 Bratislava
42 7 28 16 49
Fax: 42 7 28 83 13

This Center is a multidisciplinary evaluation clinic and intervention center. Where infants and very young children are concerned, intervention is focused upon physical therapy. There is an integrated preschool program. The center also has a Montessori teacher with special training for children with disabilities and lots of Montessori equipment, but this teacher only works on 1:1 basis with children with special needs. Vladimir Dockal, Ph.D. (psychologist) is director and, apparently, principal investigator on grants supporting the Center. Zlatica Janoutova (pediatrician) is the co-director and chief medical person at the Center. The Center is supported in part as a research project with grant money out of a child psychology institute in Bratislava: (Vyskumny ustav detskej psychologie a patopsychologie; Zahradnicka 93; 821 08 Bratislava). Its programs and resources are, therefore, subject to the impact of available funding. The staff of this Center are interested in doing joint educational conferences with staff from the Infant Center and the two sites have also shared professional staff on at least one occasion. There might be the possibility for developing linkages between parent groups (once developed) from each site.

Secondary Teachers Training School for Special Education

This is a high school level (4 years from age 14 to 18) vocational training school for students interested in careers as kindergarten (i.e., preschool) teachers or as before or after school child care teachers and providers. There are about 500 students at this site, and there are apparently one or two other such schools in Slovakia. In spite of its name, it does not have a focus on special education of children with disabilities. Students who qualify (and wish to) may go on to university for more advanced studies; others go to work in preschools and child care centers. This type of school provides a possible infrastructure and pre-service training setting to teach about inclusive education and issues of children who have special needs and their families.

Center of Early Diagnostics and Therapy

We did not visit this center, but heard about it through Dr. Matulay's talk at the seminars on Monday 5/10/93. This is apparently another multidisciplinary evaluation clinic and early intervention center in Bratislava. Its founder and director is Karol Matulay, M.D. (neurologist, professor and respected emeritus scholar). The program emphasizes a multidisciplinary and early identification model and seems to have a family centered approach. Dr. Matulay was very interested in the idea of students providing respite care for families which was mentioned in one of our presentations.

Possibilities seem to exist for cooperative work among the **Infant Center, Bratislava Children's Center, and the Center of Early Diagnostics and Therapy** around joint conferences; shared human, informational, and other resources; combined clinical databases or joint research; development of parent-professional partnership models; and advocacy for change. These three sites could also be settings for the further refinement of state-of-the-art multidisciplinary clinical models for children with complex conditions.

Methodological Educational Center

Budmerice near Bratislava

Our initial night's welcoming dinner was held in this center which is an administrative office and meeting place for the in-service education of teachers. Its staff seem to be involved in curriculum and program development for public schools. This is the place where Margita Gazdikova works.

Budmerice Castle

House of Writers

Budmerice

Prior to our welcoming dinner, we joined the Bratislava team for a tour of this retreat for members of the Writers Union. All published writers who belong to the Writers Union may utilize this retreat as a place to come and think, write, relax, and meet with other people.

Family/Consumer Groups

The highlight of our first full day in Slovakia and, in some respects, of the entire visit was the opportunity to meet with about 30 parents and families who attended the second meeting for families organized by the staff of the Infant Center in Danajksa Luzna. The first gathering of this sort had occurred in October 1992 as a consequence of the discussions and priorities established during the June 1992 visit of the Bratislava team to the conference at Georgetown. On that occasion, the Infant Center staff had been surprised and pleased with the level of interest of families, with the diversity of the turnout with respect to the ages (infancy through adolescence) and disabilities (physically and mentally challenged; Down syndrome; autism; cerebral palsy), and, most of all, with the frankness and feeling with which families related their own stories. The meeting which we attended resembled family support meetings anywhere in the United States with a sharing of food, music and entertainment, experiences, and the empowering observation that one is not alone.

We told our stories and our visions for the future of our children, but not before hearing from a number of the parents attending the meeting as they stood in turn and spoke of their own experiences.

The parents of Susan, age 6, described worries beginning when Susan was five months old and a pediatrician who tried to play down their concerns. By eight months of age they "were lucky to get to the Infant Center" with Susan where her parents' suspicions of cerebral palsy were confirmed. It was a "shock for us" but the doors were opened to therapy and educational interventions. Though Susan does not speak, she has been able to attend kindergarten with typical children and her parents hope she will go on to first grade. They feel compelled to help their child "live in a normal world."

Pauline's (age 3) parents talked about acceptance and making rehabilitation a part of family life. They dislike the word "disabled" and feel that "to go further we must build on something positive and that starts with acceptance." Pauline's mother believes that commitment to overcome challenges needs frequent renewal. Renewal comes in part through the moral support from other families. Other families helped Pauline's family obtain the gasoline needed to drive to the family meeting, and when word spread that they needed a seating device for Pauline, the International Women's Club of Bratislava raised the money for its purchase.

The mother of a 15 year boy with Down syndrome (among seven children) recalled not being told of her child's diagnosis at first because fifteen years ago there was "not such good care as there is today." When her son was three months old, he became ill and the doctor said her "child would die within a year." He attended a special needs preschool, but did not adapt well and was kept home.

Members of a family support club in a nearby village (Senec) told of the club's organization through the social welfare office and the objective of encouraging families to lead the organization. One mother of a child with cerebral palsy who attends the club described how important it was to identify with other families to share both joys and pain.

Marta Carnogursku, wife of the former prime minister of Slovakia, was a member of our contingent at the family meeting. She is a warm, observant supporter of the activity of the Infant Center. After listening to all of the parents relating their stories, Ms. Carnogursku commented that she was "staggered that these Slovak parents would speak out so openly and frankly about such personal matters." She went on to point out that such self-advocacy was never permitted, much less supported in the communist regime.

The day following the family meeting while we were touring the Infant Center and meeting with its staff, a mother of a two year old boy called to see if she could meet with us. She had attended the previous day's meeting and had heard that we were in the village to see the Infant Center. Her son had atrophy of his left leg due, in his mother's opinion, to the infiltration of an intravenous medication administered during a hospitalization when he was 12 months old. He now has a mild physical disability as a consequence. She was full of angry feelings about what had happened to her son and wondered what recourse a mother in the United States would have under similar circumstances. She was also anxious to confirm that she had done everything

possible to provide rehabilitation for her son. This incident led to a discussion with Center staff about the value of this woman's anger and resourcefulness as indicators of leadership potential rather than regarding her anger as a pathological indicator of a failure to accept what had happened to her son. Polly Arango noted, referring to this mother, "that was me ten years ago." With our encouragement, Dr. Frecerova made plans to meet with this mother later in the week and try to interest her in helping with efforts to organize other parents.

Our experiences in Slovakia gave the impression that there are few opportunities such as the family meetings that the Infant Center has sponsored. The Bratislava Child Center which we visited on the third day of our stay was planning to support a weekly meeting in which parents could come to the Center for informal discussions with "experts" and with other parents. These efforts are sound and honest beginnings to the process of empowering families which may crystallize into larger sources of advocacy and self-determination or spawn new ones. If that is to happen, the parent groups must become true organizations in which the leadership is held by the parents themselves and in which the professionals play a supportive or partnering role. Parents must be identified and even trained to be leaders and then given the means to organize and plan. Individualized parent-to-parent networks could be established at the Infant Center and at the other programs we visited in Slovakia. Parent advisory councils for needs assessment, planning, and quality assurance at the various sites could be established to develop a cooperative partnership between the professionals in each center and families. The Chance for Every Child Foundation provides another opportunity for parents as partners and leaders by insuring that the foundation's board has at least three members who are parents or consumers. We attended a wonderful meeting of families and participated in a fascinating seminar for professionals during our stay in Bratislava. In the future, efforts could be made to organize an educational meeting that included parents and professionals both as planners for the meeting as well as in the role of teachers and listeners.

Health Care for Children with Special Needs

The cost of care is not an obstacle to either routine primary or specialized health care for children with special health care needs as all citizens of Slovakia are afforded free health care. Where specialized care is available, it is provided by knowledgeable, well-trained individuals. However, most tertiary and many secondary care resources are concentrated in Bratislava and not easily accessible to families in more remote areas of the country. For such families, the costs of travel including transportation and lodging prohibit seeking care away from their own community or region. A physician friend of Dr. Frecerova joined us for the seminar on our second day and on our tour of the Bratislava Children's Center on the third day. She practices pediatrics in a town in the Carpathian Mountains and noted that few specialized medical or educational services are available to her or her patients. Many of the parents at the family gathering in Danajská Luzna mentioned physicians who did not take their concerns seriously or regarded their children as "hopeless cases." Though similar comments would be heard at a meeting of parents in most areas of the United States, there are indications that medical (and other professional) training in Slovakia provides little exposure to the development of communication skills and empathetic attitudes towards families much less to the notion of a true partnership between professionals and families.

We experienced or heard about four solid examples which modeled multidisciplinary approaches to assessment and intervention—the Infant Center in Danajská Luzna, the Professor Matulay Institute, the Center for Early Diagnostics and Treatment (where Professor Matulay is founder and director), and the Bratislava Children's Center. Each of these sites have center-based teams that include pediatrics, pediatric neurology, psychology, and physical therapy while several add speech/language specialists and educators. The Professor Matulay Institute and the Bratislava Children's Center have integrated preschool settings as educational models linked to their diagnostic services.

The Specialized Infant Center in Danajská Luzna has been an outreach facility of the Institute for Tb and Respiratory Diseases for many years. It was once a place in which care for

infants and small children could be provided while their mothers were being treated for tuberculosis at the main hospital. Following the more successful treatment and control of tuberculosis, the facility gradually evolved as a refuge for children in need of social care and as a multidisciplinary center providing evaluation and early intervention for children with developmental disabilities. The latter role constitutes over half of the in-patient census and the majority of the out-patient visits to the Infant Center. Depending on the nature of a child's disability and that a family lives from the facility, children may be hospitalized for a period of initial evaluation and treatment or may be managed from the beginning on an out-patient basis. For families living a greater distances, mothers may come and stay at the Infant Center during the last days of their child's hospitalization in order to learn therapeutic methods to be carried on at home. In other cases, the entire therapeutic program may be carried out through daily or weekly visits by parents and their children to the Center. Partly as a result of priorities identified by the Bratislava team at the June 1992 conference in Washington, D.C., several new, modular buildings have been added to the Infant Center site providing new treatment space and a comfortable waiting area for families arriving for out-patient treatment. Families utilizing the Infant Center clearly attested to the importance to them of having access to a team of highly skilled and experienced professionals who offered actual interventions for their children. The intervention model was clearly one combining hands on treatment by therapist combined with training of parents to deliver the same treatment program at home. There is a strong emphasis on physical therapy and a philosophy of "cure" rather than habilitation that seems to be part of the Vojta Method practiced widely in both Slovakia and the Czech Republic. Though the emphasis on early intervention is important, the promise of cure may burden parents with feelings of failure or incompetence (not to mention major disappointment) when impairments persist in their child. Concentration upon the motor system, though critical to fostering competence and independence in infants and young toddlers, may need to be balanced with support for intervention strategies focusing on other domains such as communication, cognition, and social interaction.

The Bratislava Children's Center was founded in 1990 with one room and a small staff. It has grown to occupy most of a large, one story building with pleasant grounds in a suburban area of Bratislava, and now has a staff of twelve including psychologists, pediatrician, consulting neurologist, physical therapists, and special educators. Speech pathology is a relatively new field in Slovakia, but the Children's Center has a speech pathologist who is also a professor at the university. Since the program is "under" the Ministry of Education and not the Ministry of Health, the physician on the staff can spend as much time as necessary with her patients and their families. About 360 children up to about 10 years of age are followed in the outpatient clinics at the Children's Center with about 20 children seen each day. Many visits are for therapy, mostly physical therapy, and they occur as frequently as "the child's mother is able to come—daily, weekly, monthly, etc." Referrals come from a variety of sources though many are directly from parents who have heard about the Center.

Habilitative equipment seemed to be very difficult if not impossible to find. One family in need of a simple seating device found it both unaffordable and unavailable. When money was raised to help with the purchase, the device was obtained from Vienna. We met several children with cerebral palsy and spina bifida none of whom had orthotic devices. Equipment to help with positioning of children on the floor, with seating, or with ambulation was not in evidence.

The existing multidisciplinary teams with which we had contact might be fruitful niduses for further development including the establishment of parent advisory councils and the development of networking between the teams. The teams might expand their sharing of professionals not available on every team such as speech pathologists. Efforts to expand into areas such as feeding and nutrition, orthopedic care, adaptive equipment, audiology, and ophthalmology might be nourished in the future perhaps utilizing the resources of the Institute for Tuberculosis and Respiratory Diseases. Finally, finding ways to support connection between the resources in Bratislava with more remote parts of the country through outreach clinics as both service sites and training opportunities might be investigated to begin to disseminate enhanced specialized services and skills.

Inclusion in School and Community Settings

Both the Bratislava Children's Center and the Preschool at Professor Matulay's Institute have excellent integrated preschool programs. Though the model is one of "reverse mainstreaming" since these programs are located in settings that serve children with special needs, the ratio of typical children to those with disabilities is high in both settings. The staff are well-trained and their approach embraces all the children as equal participants. The integrated preschool at the Professor Matulay Institute is in its second year with 11 children age 2 1/2 to 4 years of age. There are 8 typical children and 3 with disabilities (all have Down syndrome). At first all of the typical children were children of employees of the Institute, but gradually other children are being enrolled and there is now a waiting list for places.

In a brief meeting with the director and staff at Professor Matulay's Institute, we were told of hopes to extend the inclusionary model beyond kindergarten (which means preschool from about age 3 to age 6) into the elementary school years. However, everyone seems to acknowledge greater obstacles to making inroads into the already highly structured and regimented primary and secondary schools. The school system in Slovakia like many European countries involves strong, early emphasis on academics and early tracking of children into academic or vocational pathways. Also, prior to 1989, school methods were unified as a matter of policy throughout the country and "alternative" models were not permitted. Nearly all "alternatives" have developed in the short time since the political changes in 1989. It was difficult for parents and professionals we talked with to imagine how our model of full inclusion throughout the primary and secondary school years could be implemented in Slovakia. There was from some a sense of wonder and disbelief that our own children attended regular classes in regular schools. Some of the professionals on the team seemed to believe that our children were somehow more "high functioning" to permit them to participate in regular classes. They seemed less able to grapple with the notion of inclusion as a civil right or with the idea that degree of disability is not an issue for us. During a meeting with the staff at the Bratislava Children's Center we were told of a Scottish group that was starting two experimental integrated schools called "Healthy School" that would begin with the first grade.

We found everywhere a natural, protective feeling on the part of parents whose children were living at home. On the one hand, most parents seemed to resonate with the idea of inclusion and of their children's fullest possible participation in the community. On the other hand, parents were concerned about safety and security and about protecting their children from ridicule and rejection. These feelings seemed to motivate preferences for some parents for community settings and activities designed for children or adults with disabilities, staffed by people familiar with their children's needs, and protected by separation from the rest of the community. Therefore, separate special education, day habilitation centers, sheltered workshops, and small group homes make some parents feel more comfortable.

There was no information available from those with whom we met on this trip about the numbers of children with disabilities living in residential or institutional settings. There are no very large institutions of the type that flourished in the United States during the past 100 years, but there are smaller "hospitals" and rehabilitation centers. The Infant Center in Dunajska Luzna has had considerable success arranging for the adoptive placement of children with disabilities whose birth parents had relinquished their parental rights. One such adoptive family traveled all the way from the Tatras Mountains to attend the family meeting in Dunajska Luzna with the three small children they have adopted with support from the Infant Center.

Policy, Planning, and Training

So much political change has occurred in Slovakia in the past three and one half years, that national policy with regard to children with special health care needs is not yet clearly articulated. Several members of the Bratislava team attending the Georgetown conference in June 1992 as members of the Slovak government (Drs. Sulcova and Sabova) are no longer a part of the current administration which took power shortly after the Georgetown meeting. There was

some concern that the current government would favor a return to or continuation of a more centralized bureaucracy. This might result in less support for the development and dissemination of alternative models for education or for health care services. However, most everyone with whom we talked about politics felt that continued change in leadership was likely before a more long term political balance was achieved. There are numerous political parties at present many of which simply represent one or another special interest. A gradual "shake out" and consolidation into fewer parties is expected. One of the problems in Slovakia which exists in other areas of eastern Europe is that most of the experienced politicians were members of the former communist regime so that the newly emerging political groups have few seasoned political professionals as leaders. On the other hand, for the time being, efforts such as those described here that are taking place at the grass roots level are permitted to continue. Under the present circumstances, the development of leadership and strategic planning skills among parents and among involved professionals would seem important in preparation for the time when national policy is ready to respond.

With a relative lack of national policy initiatives (and, therefore, federal funding) that promote newer models of education, health care, and other services for children with special health care needs, private and local efforts are crucial. We were pleased to see the development by Dr. Frečerová of the Chance for Every Child Foundation and her ability to utilize powerful networking connections such as the International Women's Club to help direct sources of private funding towards efforts like the Infant Center in Danajská Lužná.

Finally, there is in Slovakia an educational infrastructure on which to build training programs important to families of young children with special health care needs and a generic system of family support that is light years ahead of anything in the United States. In the first instance, there are secondary level "high schools" such as the one we visited in Bratislava for training students to become teachers of preschool children or child care providers. These schools could easily incorporate into their curricula not only information about preschoolers with special needs, but ideas about including such children in regular settings with their peers. In the second instance, child care leave is provided to all mothers following the birth of any child. This paid leave lasts for three years in every case and is extended considerably if a child has a disability. This understanding that all families of young children need support in parenting is easily extended to a consideration of the kinds of supports that families of children with special needs may require. However, to some degree, the "other side" to the extensive (in duration) financial support provided when a family has a child with a disability is that very little else is available in the community for that child.

Summary of Prague Visit by Polly Arango and Carl Cooley, M.D. May 12-16, 1993

People With Whom We Met: *=original Prague 2 team

- *Vladimir Komarek, M.D. (Chief of Pediatric Neurology, Motol Hospital)
- * Jan Polecha, Ph. D. (Physicist; Chair, Prague 2 School Commission)
- * Ludek Vrba, Ph.D. (Psychologist; Facilitator, ACCORD)
- * Karel Koblic, Ph.D. (Chief of Prague 2 Health Care Commission)
- * Vera Sevcikova, M.D. (Pediatrician in Prague 2)
- * Tomas Jung (Director of Health and Social Care, Min. of Health)...telephone conversation only
- * Gabriela Bezdekova (former health official; mgr., Searle Pharmaceuticals, Czech Republic)
- Pavla Boxova (Parent of child with Down Syndrome; staff at JDC, since left that position)
- Lubash & Katka Doretsova (Supported employment proponents; Katka has sister with mental illness)
- Vlasta Stupkova (Physiotherapist and inclusion supporter)
- Katerina Ciharova, M.D. (Chief, Medicine for Foreigners, Motol Hospital)
- Jaroslav Kotal (principal, Londynsky 34 School - "The Free School")
- Jarmila Cechnerova (Mother of child with disability; ACCORD President)
- Lena Andova (Mother of child with CP; TV host for disabilities show)

Places Visited in Prague (5/12/93 - 5/16/93)

Motol Hospital 18 Prague 5

Dr. Komarek is Chief of Pediatric Neurology at this large tertiary care hospital in a Prague neighborhood. A general and teaching hospital, it has a specific clinic for health care for foreigners. A new medical center/hospital is nearing completion on this site. It is a possible site for an interdisciplinary clinic for children with special health needs under the supervision of Drs. Komarek and Ciharova.

American Jewish Joint Distribution Center (JDC) Myslikova 7 Prague 1

Located in downtown Prague, the JDC provides grants and supports and facilitates trainings on inclusion between the Czech Republic and the United States. Madeline Will is a US contact. The JDC has sponsored visits by a variety of US specialists in inclusion and supported employment. It might be able to manage more effective coordination of visits and technical assistance from multiple sources and projects.

Na Dekance 2 Special Kindergarten: Materska Skola Prague 2

A special kindergarten within a regular kindergarten, with some interest in integrating, or at least providing some integrated activities if appropriate and adequate supports are put in place. Its classrooms and playgrounds are side-by-side on the same property in the center of Prague. Staff from both schools attended a June 1993 training by Mary Schue on inclusion in schools.

"Free Primary School"

Londynsky 34
Prague 2

An experimental primary school with a focus on learning English, including youngsters with learning and other disabilities in "regular" classrooms, and providing an education based on freedom and individual learning. Jaroslav Kotal is the principal and a classroom teacher, with a real interest in providing inclusion for youngsters with disabilities if he is given sufficient supports.

Modry Klic (Blue Key)

SPMP Praha 4
Kamyk, Smolkdva 567/2, 142 00

An attractive new community program located on the outskirts of Prague near many large apartment complexes. Blue Key provides a day and living program for about 30 children and adults with disabilities. Most of its activities take place at the center and include plans for a sheltered workshop, garden, and enlargement of residential capacity. It was created by parents, a parent is the director, and it receives moral and financial support from government and private industry. It is considered a model program.

ACCORD Parent Group

Meets at the Prague 2 Town Hall, with Ludek Vrba, Ph.D. as the facilitator. Jarmila Cechnoerva is the president. ACCORD has recently been given 2 rooms which the group wants to make into office, library, and informal meeting space. ACCORD might also receive a grant from the government; the group must first develop a program which the grant will support.

Bohnice Institute

Bohnice, Prague

A large (42 buildings) residential facility for people with mental illness on the outskirts above Prague. For the last 2 years, Bohince has been the site of the Prague Inclusionary Arts Festival, featuring drama, dance, and music programs that include adults and children with disabilities, to which the public is invited.

The Homes of 3 Families: Pavla Boxova, Lena Andova, and Vladimir Komarek

At the families' invitations, we visited their homes, meeting children, spouses, and grandparents; talking about health and education issues that impact the families or other families that they know, and enjoying refreshments or a meal. It was a treat and an honor to be in their homes and to be shown such hospitality and friendliness.

Family/Consumer Groups

We attended a meeting in the Prague 2 Town Hall of ACCORD, a parent group in Prague 2 that is led by Ludek Vrba, a psychologist. About 15 parents were there. ACCORD's President is Jarmila Cechnerova, a parent. ACCORD has received great support from the Prague 2 team, has recently been given two rooms for offices by the Prague 2 government, and has the possibility of receiving future grants. We presented a small slide show that focused on parent involvement, reliable alliances within and between families and professionals, and utilizing parent/professional partnerships to create systems change. Questions from the parents centered around how the United States has developed a variety of supports (legal, community, financial, educational, emotional) for including people with disabilities in school and community life. Later, the real parent meeting began. With the possibility of obtaining part of a building for the use of ACCORD, there was a great deal of discussion (and disagreement) about its use. It appears that most families would like to sponsor a day program for their sons and daughters with disabilities who now have few if any opportunities beyond their home. Several professionals in the room argued that it should be a place for inclusionary kinds of activities. As in all parent groups, there were many opinions and no conclusions were reached. We were told by Pavla Boxova and others that almost every section of Prague has a parent group like ACCORD. There seems to be a possibility that the local Prague parent groups and SPMP, the national parent group that receives funds from the government, could be encouraged to meet to define common issues.

Community Living for People with Disabilities

There is a great deal of interest in Prague about the importance of encouraging and supporting people with disabilities in the community. Whether parents, policy makers, teachers, advocates, or health professionals, they are seeking ways to ensure that people with disabilities can partake in and enjoy the freedoms that Czech citizens care so much about.

At this time, however, according to families, advocates, health officials, and our own brief observations, people with disabilities are not a visible presence in Prague. That is not very different from many cities in the United States. Neither adults nor children are not on the street, in stores or restaurants, at community events, working at jobs, or taking part in inclusive recreation activities. Whether children or adults, they live at home with their families and seldom take part in education or community activities. Or they live away from their homes and families in institutions. Most of the children or adults with disabilities who do attend schools or day programs do so in segregated settings. A very few young children with mild disabilities (Down Syndrome, mild Cerebral Palsy, dwarfism, hydrocephaly, etc.) attend regular schools, Jarmila Cechnerova's son, for example, in integrated classrooms or typical schools with separate special education classes.

Several private/public initiatives have created handsome community living programs for people with disabilities, but they tend to be separate from the larger community and serve only people with less severe disabilities. For example, we visited Modry Klic (Blue Key), a new day and overnight program for about 30 children and young adults with disabilities. Founded and directed by a parent organization, Blue Key is a bright, well-appointed building, with about 20 staff members, a plan for supported employment and a sheltered workshop, and expectations for providing a permanent home and work for its residents.

Most of the professionals and families whom we met believe that inclusion of people with disabilities in Prague life is possible—if appropriate supports and community education are present. The American Jewish Joint Distribution Center (JDC) has already developed two community living arrangements in which 6 people with mild mental retardation are living in flats in Prague. The JDC has also sponsored a series of training institutes that engage professionals and families in learning about and planning for supported living and supported employment activities. We also visited the second annual barrier-free arts festival at Bohnice, a large (40 buildings or so) institution for people with mental illness just outside Prague. We saw theater, dance, and arts productions by or for people with disabilities. Several of the plays and skits were

performed by people with disabilities. One skit was performed by people with mental retardation who participate in Oasis, a drama program. The audience and participants seemed to enjoy the inclusive community they had formed, and several of the leaders with whom we spoke indicated an interest in bringing people with and without disabilities together through arts activities.

It should be noted, however, that, as in the United States, most families who have older sons and daughters with disabilities living at home with them question the viability of total inclusion—and prefer that the first community living that their children experience takes place in a protected setting.

Health Care for Children with Special Needs

The families and health care professionals with whom we spoke indicated that basic primary and specialty care is available for all children with special health care needs if they can access a clinic or hospital. However, Lena Andova, a parent, has heard from many families who live both within and outside Prague who find it extremely difficult to access the specialized health and education services their children need. For example, more complex procedures (a gastrostomy tube) are not available anywhere in the Czech Republic. Nor is equipment for youngsters who need seating, walking, feeding, orthopedic, or wheelchair assistance. While there are some individual efforts to find and retrofit equipment, it is not on a national or citywide basis. Families who have children with complicated disabilities must carry them to multiple appointments in distant parts of the city, often using public transportation. The families recommended that having one place to go for care for a child with multiple health care needs would be more efficient for everyone. Dr. Komarek indicated an interest in creating a multidisciplinary team at Motol Hospital for youngsters with neurological conditions. If successful, it could serve as a model for similar teams and clinics for other diagnoses and in other communities.

Czech traditions include natural supports that families can rely upon, especially the grandmothers, a systems element to be considered and built upon. Time after time, we witnessed grandmothers either caring for the child with a disability while the mother worked outside the home, or grandmothers who performed household chores and watched over siblings, freeing up the mother to take care of a child with multiple disabilities. (While mothers who stay at home to care for their child with a disability receive a stipend, the amount is not considered sufficient for the care of the child, and the stipend can become a societal excuse for not providing education and social opportunities to children with handicaps.)

Unlike the United States, the cost of health care, even under the new insurance plan, is not an issue at this time. However, everyone, provider and consumer alike, expressed concern about the new national health insurance plan. Some concerns were the level of reimbursement for providers; would there be cost sharing by consumers; during a transition phase, what happens to complicated cases; will all communities have access to health providers of similar quality or expertise.

Inclusionary Education.

We viewed two public schools in Prague 2 that had made efforts to involve youngsters with disabilities in their programs. At the Na Dekance 2 school, there was one kindergarten class with 18 students (one teacher, one principal, one aide/housekeeper) who had mild, mostly language-based disabilities or were considered at-risk. The children were happy and lively, the adults worked together as a team. The class was held in two very large rooms, with a large bathroom and cubby area, and a small garden with a sandbox and table and chairs. The class was separated from the nearby "typical" kindergarten in the school by a fence. The principal indicated that the two groups of children did not meet, but she understood that it might be beneficial to all of them if they did share activities and perhaps even merge in some way. She said that more staff would be required in order to do so.

We also visited the "Free Primary School"—Londynsky 34—a new school this year that has 520 students, 19 teachers, and a strong emphasis on personal freedom and responsibility, English language, and inclusion of youngsters who have diverse challenges. There are 30 children with dyslexia, 17 with learning disabilities, and 4 with mental retardation or physical disabilities. The school's principal, Mr. Kotal, expects an even greater number of children with special needs next year, but also is concerned that there must be an adequate number of trained staff in order to include and support those students successfully. Many people with whom we spoke indicated that this school is an experiment, and that its very nature (it does not give grades to students, for example) has many parents nervous. We were assured that this school, and the Na Dekance kindergarten, are rare. For the most part, children with even mild disabilities either attend a segregated school or day program (that may or may not have an educational component); stay at home with no schooling; or live in an institution. Children with more severe handicaps are almost always at home or in an institution and are not provided access to education or social opportunities. Lena Andova's child, for example, is at home with his mother all day.

Younger parents, risk-taking educators and policy makers, and most of the international education consultants who visit Prague believe that inclusionary public education can occur. For instance, families will seek an integrated nursery school, even if it is far from home, and then will look for a primary school that will include their child in regular classrooms. There is also great debate over the wording of the new national education law and its attitude toward including children with disabilities in regular school settings, according to Mrs. Polecha. As education in general continues to undergo study and transformation, as families become more involved on local school boards and in policy making partnerships with the Ministry of Education, and as small efforts at community integration grow, it is likely that more and more children with special needs can enter regular classrooms. At this stage, however, youngsters with milder disabilities will enter the mainstream quicker than those with more complex disabilities.

Partnerships Between Professionals and Families

In June, 1992, when the Prague 2 Team came to Washington for the International Congress, there was not a parent member of the team. It seems clear now that Jarmila Cechnerova, a parent, is a well-respected partner in the ACCORD activities. There is also a great bond among the Doretsovas, Vlasta Stupkova, Pavla Boxova, and Lena Andova: should they decide to take on an issue, they could be very successful. The parent/professional partnership seems strongest among those who share a common philosophy.

Policy and Philosophical Issues

Inclusion of people with disabilities in the community is a topic of great interest. In a country in which diversity of thought or action was not allowed for decades, the idea of involving people with different behaviors, mannerisms, physical attributes, and abilities in community life is a challenge. As in the United States, families who have experienced ridicule and shame (or whose children have) fear bringing their sons and daughters into a community in which attitudes might not have changed. Can a society (a state, a country, a city) proceed immediately from segregation to full inclusion, skipping over the middle developmental stage—in but not of the community? Many Czech policy makers and families believe that creating a place—a special school, a special recreational program—in the community for people with disabilities is "better than nothing. We wondered about how a country like the Czech Republic, which now is intent upon de-centralizing what was a highly centralized government might ultimately centralize some functions—consumer information and referral, or data collection, for example. It is also not clear how the idea of peer support—parent to parent groups, in which parents share their feelings openly—will be acknowledged and supported, although parents indicated that such groups and processes are important to them.

Implications for the United States

It is difficult to sort out the layers of implications of our brief, but intense exposure to families, professionals, services, and day-to-day life in Slovakia and the Czech Republic. This trip has certainly left us with a more balanced impression of the circumstances of children with special health care needs and their families in these European countries. Our past meeting in Washington and overseas contact by mail and phone provided narrow glimpses with much that was lost in translation or due to the constraints of conference format or time. This visit broadened our point-of-view immensely. This makes us more useful as resources for our friends in Prague and Bratislava, but also, we feel, more thoughtful in our activities as activists and advocates in the United States. We were reminded of the diversity of opinion among families everywhere about what is in the best interests of one's own children and the diversity of belief among professionals about what represents optimal treatment and intervention.

We have also experienced a warm, human endorsement of the notion that families are much the same everywhere. And that families who experience the challenge of a child with chronic illness or disability share many of the same emotions, aspirations, disappointments, visions, troubles, encounters with professionals both hurtful and helpful, and conclusions. We as families in the United States, the Czech Republic, and Slovakia are strengthened by our mutual support of and respect for one another and by honest, open partnerships with professionals. We can now confidently tell families we know in the United States that they have joined a network that is not only regional or national, but worldwide. Our plans for making individual parent-to-parent connections between families in Slovakia and the Czech Republic and families in the United States will be a small, but forceful manifestation of this international common thread.

As believers in the value of natural systems of support and their priority over contrived, statutory formal support systems, we were repeatedly impressed with the strength of the extended family as a support system during our visit. Grandparents were everywhere. Aunts and uncle were child care providers. In many instances this closeness was partially imposed by a 40 year history of housing arrangements which forced families to share living accommodations over several generations. However, the strong families ties beneath these associations were easy to see. Communities as well seemed to be natural and accepted systems of support in many instances. Though there was evidence that general public acceptance of the inclusion of people with disabilities in community life was still a distant goal, we experienced many specific examples of friends and neighbors doing the supportive things that come naturally in many small neighborhoods and communities. As we proceed to develop family support programs and services in this country, we must not only respect family and neighborly supports where they exist, but develop and nourish them as vital resources where they do not exist. Professional family support workers can never replace the trust, caring, and unconditional support that binds families and friends.

Health care in Slovakia and the Czech Republic is available for everyone. The degree to which this uncomplicates access to basic health services was an eye-opening endorsement of the need for health care reform in this country. Health care for all in these two countries means all. There is at the time of this writing strong concern that our own long anticipated health care reform package will not include benefits important to children with special health care needs. In fact, there are indications that we may adopt a "universal" system which does not include children with special needs at all, but requires them to "come through a different door," pass eligibility requirements, and then receive financial support through a separate system. Europeans whom we talked to were dumb-founded that our country has such incredible technical resources in health care, that we have come so far in the area of disability rights, and that we are still not ready to say that everyone has a right to the health care that they need through a single, universal system. On the other hand, as these two countries move to decentralize services systems and, in

the case of the Czech Republic, to privatize their health care system, we were frequently reminded that certain centralized functions may need to be maintained such as the regulation of standards and quality, the collection and distribution of data, and some aspects of long term planning. As we promote and pursue the concept of community-based care for children with special health care needs in this country, we need to develop a sense of balance about resources and functions which might be better maintained or performed on a regional or central level.

Just as health care is a given for citizens of Slovakia and the Czech Republic, families are also respected as the foundation of community life. Families are strongly and universally supported around the activity of child bearing and child rearing. Lengthy, paid maternity leave is provided to all women during the latter parts of pregnancy and child support stipends continue during the early years of every child's life. When a child has a disability, the duration of stipends increases. While this system functions upon the assumption of traditional roles for mothers as caregivers and fathers as breadwinners and to some degree substitutes for adequate community services and supports for children with special needs, it is still based on the notion that societies need to "walk the walk" when it comes to "family values." As we struggle for tangible sources of support for families stressed by the challenges of a child with special needs in the United States, we must stop and consider whether we would be wiser to approach this issue as advocates for families in general and strong generic supports for families with children.

Recommendations, Logistics, and Resources

1. Model the Parent/Professional (or Consumer/Professional) Partnership. Our experiences in our states and at the national level in the United States have shown us that systems change for people with disabilities occurs most effectively when families and consumers work in partnership with professionals and policy makers. We, therefore, recommend that future consultants should themselves model the consumer or parent/professional partnership. We are convinced that our team—a parent of an adolescent with multiple disabilities and a physician who is also the parent of a child with Down Syndrome—had a greater impact than either of us could have had alone. We recommend the parent or consumer/professional team for education, health, and community living consultants. In fact, we believe that the presence of one member of the team who lacks a title or a profession is an invaluable lesson to the Czech or Slovak professionals about the strength and expertise of families and consumers in making decisions about their children and/or themselves.

2. Utilize the Expertise and Experience of Czech and Slovak Families and Professionals. We suggest that future seminars and workshops sponsored by international organizations model the parent/professional partnership by also including Czech counterparts in seminars and teaching activities. This will provide credibility and support to Czech and Slovak leaders, parents, and professionals, who are committed to inclusion.

3. Build Strategic Planning Skills We heard from several families and professionals that they are now ready for learning how to take what they have learned about inclusion and implement it. But first, they believe that they need training in: creating a shared vision; strategic planning; priority setting; developing and implementing pilot projects; dissemination; replication. We suggest that teams with those skills and experiences come to Prague and Bratislava and work with families, policy makers, and health and education professionals.

4. Coordination of Visiting Consultants Those who host or meet with visitors like us expressed concern that, in many cases, there is duplication or, at the very least, no coordination (time, materials, sites, program, people) among the various visiting consultants. The coordination can occur either in the host countries (e.g., one of the ministries) or in the United States. We believe it is possible to stretch the good nature and kindness of our hosts.

Logistics

- 1. Videos** Convert videos to East European format (SECAM)
- 2. Slides** Slides work in local projectors. Bring slides in boxes and transfer to cassettes.
- 3. Materials** Clear, practical, how-to manuals on inclusion, parent support, and ways to create programs and organizations seem to be useful. We also found that teachers, students, and families enjoyed receiving English-language books of all kinds. Medical journals are in short supply with limited variety and photocopying capability varies.
- 4. Accommodations** Try to stay in pensions rather than expensive hotels.
- 5. Bratislava** For visits to Bratislava, Slovakia, fly to Prague, then bus to Bratislava. Or fly directly to Bratislava. No need to go through Vienna, and it creates a hardship for hosts.
- 6. Gifts** Modest gifts for adults and children are nice. We gave our Slovak and Czech hosts books and small gifts from our states (maple syrup, Indian jewelry, cowboy kerchiefs, t-shirts, books, etc.). We also distributed hundreds of stickers to children with English words or pictures of typical US or state items, plus many small story and picture books to classrooms and families.
- 7. Cameras** Still and video cameras are useful for documentation and memories.

Resources Carried from the United States

Videos: Three different videos were carried. Two copies of each were converted to SECAM for use in European machines. One copy of each was carried in US format. We left one copy of each of the videos with Dr. Frecerova and her Chance for Every Child Foundation in Bratislava. In Prague, we gave a copy of each of the videos to ACCORD. We gave the US format videos to the JDC, which has a US machine.

- Family Centered Care—A 30-minute video from the Association for the Care of Children's Health (ACCH) about providing health care to children with special needs in a family-centered way with Stories about families from throughout the US.

- Kids Belong Together—A 24-minute video about secondary school inclusion from Inclusion Press, Toronto, Canada.

- Parents Helping Parents—A 24-minute video produced by Parents Reaching Out (PRO) of New Mexico. Families, physicians, and counselors discuss the importance of providing support for parent-to-parent groups and activities.

Books: At least two copies of every book were carried and given to A Chance for Every Child in Bratislava and ACCORD in Prague.

- Action for Inclusion (Inclusion Press, Toronto). Specific ways to improve all schools by welcoming youngsters with special needs. Also available in French and German.

- Family-Centered Care (Association for the Care of Children's Health/ACCH). Often called "Big Red," this is the original edition of the "bible" of how to provide family-centered care to children with special health care needs.

- Parent/Professional Collaboration (University of Vermont). Specific examples of ways that families and professionals can form partnerships to work on behalf of children with special health care needs.

- Woodbine Press Books for parents (4 sets - two in Bratislava and two in Prague) These books were generously provided by the publisher.

 - Babies with Down Syndrome: A New Parents Guide.

 - Child with Autism: A Parents Guide

 - Child with Cerebral Palsy

 - Child with Epilepsy

- Supporting Parent Training: A Skill Building Workshop by N. DiVenere; Parent to Parent of Vermont, Winooski, VT

- Parent Articles for Early Intervention edited by M.D. Klein, M.Ed.; Communication Skill Builders, Tucson: 1990

- A Vision of Early Care and Education for Young Children with Disabilities and their Families in New Hampshire by the Early Care and Education Committee of the New Hampshire University Affiliated Program; University of New Hampshire, Durham, NH: 1993

- Enabling and Empowering Families: Principles and Guidelines for Practice by C. Dunst, C. Trivette, and A. Deal; Brookline Books, Cambridge: 1988

- Support for Caregiving Families edited by G. H. S. Singer and L. K. Irvin; Paul Brookes, Baltimore: 1989

- Many, many simple children's stories about the Southwestern United States. We gave these to classrooms, to children, to families.